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Patient #: __ __ __

Application Date: __ __ __

Screening and Natural History of Patients with Fibrous Dysplasia and the McCune - Albright Syndrome

Surgeon Information

Last Name	[ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]
First Name	[ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]
Street	[ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]
City	[ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]
State	[ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]
Zip Code	[ ][ ][ ][ ][ ]
Country	[ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]
	(Country Code) (Area Code/City Code) (Number)
Home Number	[ ][ ][ ][ ]-[ ][ ][ ][ ]-[ ][ ][ ][ ][ ][ ][ ][ ][ ]
Work Number	[ ][ ][ ][ ]-[ ][ ][ ][ ]-[ ][ ][ ][ ][ ][ ][ ][ ][ ]
Alt Number	[ ][ ][ ][ ]-[ ][ ][ ][ ]-[ ][ ][ ][ ][ ][ ][ ][ ][ ]
Fax Number	[ ][ ][ ][ ]-[ ][ ][ ][ ]-[ ][ ][ ][ ][ ][ ][ ][ ][ ]
E-mail	[ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]
Specialty	[ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]

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Application Date: __ __ __

Patient Demograftic Information

Patient's Last Name [ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]

Patient's First Name [ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]

Patient's Middle Name [ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]

Street [ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]

City [ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]

State [ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]

Zip Code [ ][ ][ ][ ][ ][ ][ ][ ]

Country [ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]

Home Number (Country Code) (Area Code/City Code) (Number)
[ ][ ][ ][ ][ ]-[ ][ ][ ][ ][ ]-[ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]

Work Number [ ][ ][ ][ ][ ]-[ ][ ][ ][ ][ ]-[ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]

Fax Number [ ][ ][ ][ ][ ]-[ ][ ][ ][ ][ ]-[ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]

E-mail [ ]

Date of Birth [ ][ ]-[ ][ ]-[ ][ ]
mo day yr

Gender [ ] male [ ] female

Race [ ]American Indian or Alaskan Native
[ ] Asian or Pacific Islander
[ ] Black [ ] Hispanic [ ] White

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Application Date: __ __ __

Fibrous Dysplasia History

1. When was your patient diagnosed with FD? Date: [ ] / [ ] / [ ]

2. What were the symptoms at the time?
   (check all that apply)

[ ] pain	[ ] fracture	[ ] deformity
[ ] limp	[ ] swelling	[ ] abnormal growth
[ ] visual or hearing loss	[ ] headache	[ ] none

3. How was the diagnosis made?
   (check all that apply)

   [ ] x-ray

   [ ] CT

   [ ] MRI

   [ ] bone scan

   [ ] medical history (for example: bone disease in the setting of MAS)

   [ ] biopsy

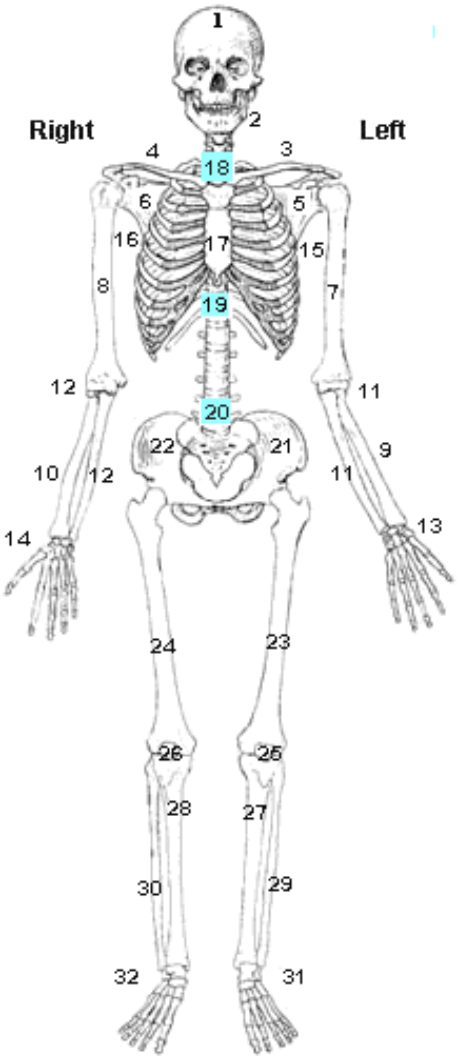
   [ ] other, explain:

   _____

   _____

   _____

4. What bones were involved at the time of diagnosis? Indicate on the skeleton. Number the fractures sequentially. That is, the first fracture your patient had is number 1, the second is number 2, etc. If your patient has had multiple fractures at a site, indicate it. For example, one site may be fracture 3 and 5.



[ ] 1.Skull
[ ] 2.Mandible (Jaw)
[ ] 3.Left Clavicle (Collar bone)
[ ] 4.Right Clavicle (Collar bone)
[ ] 5.Left Scapula (shoulder blade)
[ ] 6.Right Scapula (shoulder blade)
[ ] 7.Left Humerus (Upper arm)
[ ] 8.Right Humerus (Upper arm)
[ ] 9.Left Radius (Forearm)
[ ] 10.Right Radius (Forearm)
[ ] 11.Left Ulna (Forearm)
[ ] 12.Right Ulna (Forearm)
[ ] 13.Left Hand/Wrist
[ ] 14.Right Hand/Wrist
[ ] 15.Left Ribs (1-12)
[ ] 16.Right Ribs (1-12)
[ ] 17.Sternum (breast bone)
[ ] 18.Cervical Spine (Neck)
[ ] 19.Thoracic Spine
[ ] 20.Lumbar spine (lower back)
[ ] 21.Left Pelvis
[ ] 22.Right Pelvis
[ ] 23.Left Femur (Thigh)
[ ] 24.Right Femur (Thigh)
[ ] 25.Left Patella (knee Cap)
[ ] 26.Right Patella (knee Cap)
[ ] 27.Left Tibia (Lower leg large bone)1
[ ] 28.Right Tibia (Lower leg large bone)1
[ ] 29.Left Fibula (Lower leg small bone)
[ ] 30.Right Fibula (Lower leg small bone)
[ ] 31.Left Foot/Ankle
[ ] 32.Right Foot/Ankle

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Application Date: __ __ __

5. Did your patient have symptoms prior to the diagnosis?

   [ ] yes [ ] no [ ] Not Available
   (if no, go on to question 7)

6. When did the first symptoms occur(approximate date)?

   Date: [ ] / [ ] / [ ]

7. What are the current symptoms?

[ ] pain	[ ] fracture	[ ] deformity
[ ] limp	[ ] swelling	[ ] abnormal growth
[ ] visual or hearing loss	[ ] headache	[ ] none

8. Has your patient had any spinal problems?

   [ ] scoliosis [ ] kyphosis [ ] Vertebral Fracture
   [ ] Low Back Pain [ ] other, explain: _____
   [ ] none
   (if none, go on to question 9)

   List below type of treatment: either conservative (brace,others) or surgical (type of demcompression and/or stabilizatoin procedure). Indicate also site and number of the affected vertebrae.

   _____

   _____

   _____

9. Has your patient had any neurological complications from his/her FD?

   [..] Loss of vision [ ] Loss of hearing [ ] Muscle weakness - body
   [ ] Muscle weakness -face [ ] Sensory [ ] None

10. Does your patient have any craniofacial deformity [ ] yes [ ] no

    If so, describe the craniofacial deformity:

    _____

11. Does your patient have any dental abnormalities, pertaining to their FD?
    [ ] yes [ ] no
    (if no, go on to question 17)

    If so, describe the dental abnormalities:

    _____

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12. Does your patient have a discrepancy in the length of his/her legs and arms?

[ ] yes [ ] no
(if no, go on to question 13)

Please provide limb measurements:
Clinical measurements:

Measurements in centimeters	Left	Right
UM (umbilicus to medial malleoulus)		
AM (ASIS to Medial Malleolus)		

Radiograftic Measurements (if available)

Measurements in centimeters	Left	Right
Humerus		
Forearm bones		
Femur		
Tibia		

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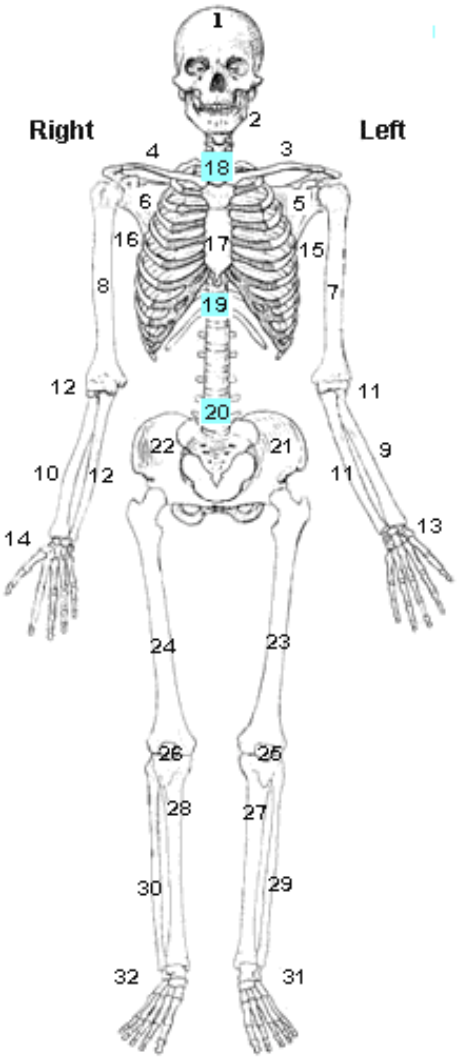
13. If patient has had fractures, indicate sites on attached skeleton. Number the fractures sequentially. That is, the first fracture your patient had is number 1, the second number 2, etc. If your patient has had multiple fractures at a site, indicate it. For example, one site may be fracture number 3 and 5.



[ ] 1.Skull _____
[ ] 2.Mandible (Jaw) _____
[ ] 3.Left Clavicle (Collar bone) _____
[ ] 4.Right Clavicle (Collar bone) _____
[ ] 5.Left Scapula (shoulder blade) _____
[ ] 6.Right Scapula (shoulder blade) _____
[ ] 7.Left Humerus (Upper arm) _____
[ ] 8.Right Humerus (Upper arm) _____
[ ] 9.Left Radius (Forearm) _____
[ ] 10.Right Radius (Forearm) _____
[ ] 11.Left Ulna (Forearm) _____
[ ] 12.Right Ulna (Forearm) _____
[ ] 13.Left Hand/Wrist _____
[ ] 14.Right Hand/Wrist _____
[ ] 15.Left Ribs (1-12) _____
[ ] 16.Right Ribs (1-12) _____
[ ] 17.Sternum (breast bone) _____
[ ] 18.Cervical Spine (Neck) _____
[ ] 19.Thoracic Spine _____
[ ] 20.Lumbar spine (lower back) _____
[ ] 21.Left Pelvis _____
[ ] 22.Right Pelvis _____
[ ] 23.Left Femur (Thigh) _____
[ ] 24.Right Femur (Thigh) _____
[ ] 25.Left Patella (knee Cap) _____
[ ] 26.Right Patella (knee Cap) _____
[ ] 27.Left Tibia (Lower leg large bone)1 _____
[ ] 28.Right Tibia (Lower leg large bone)1 _____
[ ] 29.Left Fibula (Lower leg small bone) _____
[ ] 30.Right Fibula (Lower leg small bone) _____
[ ] 31.Left Foot/Ankle _____
[ ] 32.Right Foot/Ankle _____

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Indicate age and how each fracture was treated.

Fracture # & Site	Fixation	If Intramedullary nails specify which	Cancellous or Cortical Bone Graft	Bone Graft Material	Plaster Cast
#___ ________	[ ] PS – plate & screws [ ] IN – Intramedullary nails	[ ]Rush #_____ [ ]Ender #_____ [ ]Kuntscher [ ] Zickel [ ] Gamma [ ] Locked [ ] other: _______	[ ] CAN-cancellous [ ] CO - cortical	[ ]AU – Autologous; Harvest Site: ________________ [ ]All – Allograft [ ] Commercial Filling Name____________	[ ] Yes [ ] No
#___ ________	[ ] PS – plate & screws [ ] IN – Intramedullary nails	[ ]Rush #_____ [ ]Ender #_____ [ ]Kuntscher [ ] Zickel [ ] Gamma [ ] Locked [ ] other: _______	[ ] CAN-cancellous [ ] CO - cortical	[ ]AU – Autologous; Harvest Site: ________________ [ ]All – Allograft [ ] Commercial Filling Name____________	[ ] Yes [ ] No
#___ ________	[ ] PS – plate & screws [ ] IN – Intramedullary nails	[ ]Rush #_____ [ ]Ender #_____ [ ]Kuntscher [ ] Zickel [ ] Gamma [ ] Locked [ ] other: _______	[ ] CAN-cancellous [ ] CO - cortical	[ ]AU – Autologous; Harvest Site: ________________ [ ]All – Allograft [ ] Commercial Filling Name____________	[ ] Yes [ ] No
#___ ________	[ ] PS – plate & screws [ ] IN – Intramedullary nails	[ ]Rush #_____ [ ]Ender #_____ [ ]Kuntscher [ ] Zickel [ ] Gamma [ ] Locked [ ] other: _______	[ ] CAN-cancellous [ ] CO - cortical	[ ]AU – Autologous; Harvest Site: ________________ [ ]All – Allograft [ ] Commercial Filling Name____________	[ ] Yes [ ] No
#___ ________	[ ] PS – plate & screws [ ] IN – Intramedullary nails	[ ]Rush #_____ [ ]Ender #_____ [ ]Kuntscher [ ] Zickel [ ] Gamma [ ] Locked [ ] other: _______	[ ] CAN-cancellous [ ] CO - cortical	[ ]AU – Autologous; Harvest Site: ________________ [ ]All – Allograft [ ] Commercial Filling Name____________	[ ] Yes [ ] No
#___ ________	[ ] PS – plate & screws [ ] IN – Intramedullary nails	[ ]Rush #_____ [ ]Ender #_____ [ ]Kuntscher [ ] Zickel [ ] Gamma [ ] Locked [ ] other: _______	[ ] CAN-cancellous [ ] CO - cortical	[ ]AU – Autologous; Harvest Site: ________________ [ ]All – Allograft [ ] Commercial Filling Name____________	[ ] Yes [ ] No

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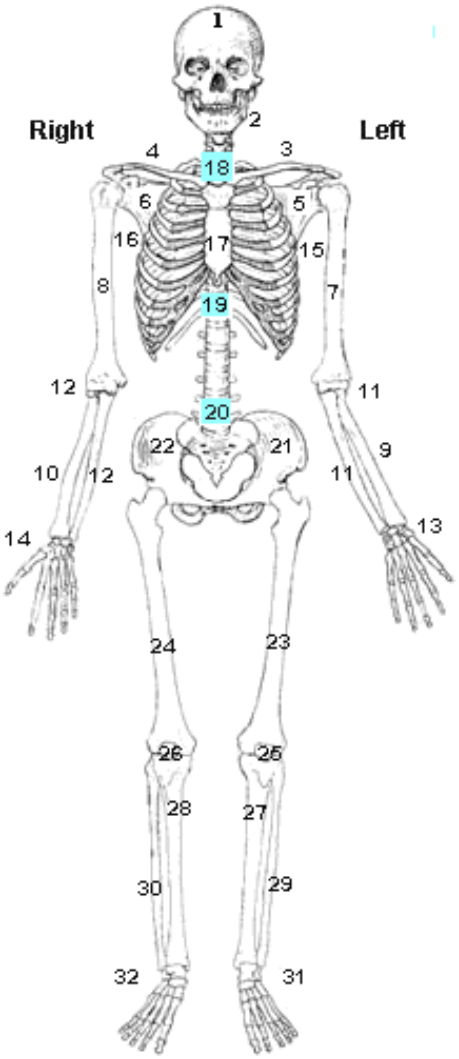
14. If your patient underwent surgery, please indicate which type(s) in the following sections(A,B,C,D). Use the numbers on the skeleton below to identify each surgery location.



1.Skull
2.Mandible (Jaw)
3.Left Clavicle (Collar bone)
4.Right Clavicle (Collar bone)
5.Left Scapula (shoulder blade)
6.Right Scapula (shoulder blade)
7.Left Humerus (Upper arm)
8.Right Humerus (Upper arm)
9.Left Radius (Forearm)
10.Right Radius (Forearm)
11.Left Ulna (Forearm)
12.Right Ulna (Forearm)
13.Left Hand/Wrist
14.Right Hand/Wrist
15.Left Ribs (1-12)
16.Right Ribs (1-12)
17.Sternum (breast bone)
18.Cervical Spine (Neck)
19.Thoracic Spine
20.Lumbar spine (lower back)
21.Left Pelvis
22.Right Pelvis
23.Left Femur (Thigh)
24.Right Femur (Thigh)
25.Left Patella (knee Cap)
26.Right Patella (knee Cap)
27.Left Tibia (Lower leg large bone)1
28.Right Tibia (Lower leg large bone)1
29.Left Fibula (Lower leg small bone)
30.Right Fibula (Lower leg small bone)
31.Left Foot/Ankle
32.Right Foot/Ankle

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Application Date: __ __ __

14. (Continued)

A) Curettage and bone grafting

Site # / Description	Fixation	If Intramedullary nails specify which	Cancellous or Cortical Bone Graft	Vascularized	Bone Graft Material	Plaster Cast
#___ ___________	[ ] PS – plate & screws [ ] IN – Intramedullary nails [ ] KW - Kierschner-wires	[ ]Rush #_____ [ ]Ender #_____ [ ]Kuntscher [ ] Zickel [ ] Gamma [ ] Locked [ ] other: _______	[ ] CAN-cancellous [ ] CO - cortical	[ ] Yes [ ] No	[ ]AU – Autologous; Harvest Site: _______________ [ ]All – Allograft [ ] Commercial Filling Name___________	[ ] Yes [ ] No
#___ ___________	[ ] PS – plate & screws [ ] IN – Intramedullary nails [ ] KW - Kierschner-wires	[ ]Rush #_____ [ ]Ender #_____ [ ]Kuntscher [ ] Zickel [ ] Gamma [ ] Locked [ ] other: _______	[ ] CAN-cancellous [ ] CO - cortical	[ ] Yes [ ] No	[ ]AU – Autologous; Harvest Site: _______________ [ ]All – Allograft [ ] Commercial Filling Name___________	[ ] Yes [ ] No
#___ ___________	[ ] PS – plate & screws [ ] IN – Intramedullary nails [ ] KW - Kierschner-wires	[ ]Rush #_____ [ ]Ender #_____ [ ]Kuntscher [ ] Zickel [ ] Gamma [ ] Locked [ ] other: _______	[ ] CAN-cancellous [ ] CO - cortical	[ ] Yes [ ] No	[ ]AU – Autologous; Harvest Site: _______________ [ ]All – Allograft [ ] Commercial Filling Name___________	[ ] Yes [ ] No
#___ ___________	[ ] PS – plate & screws [ ] IN – Intramedullary nails [ ] KW - Kierschner-wires	[ ]Rush #_____ [ ]Ender #_____ [ ]Kuntscher [ ] Zickel [ ] Gamma [ ] Locked [ ] other: _______	[ ] CAN-cancellous [ ] CO - cortical	[ ] Yes [ ] No	[ ]AU – Autologous; Harvest Site: _______________ [ ]All – Allograft [ ] Commercial Filling Name___________	[ ] Yes [ ] No
#___ ___________	[ ] PS – plate & screws [ ] IN – Intramedullary nails [ ] KW - Kierschner-wires	[ ]Rush #_____ [ ]Ender #_____ [ ]Kuntscher [ ] Zickel [ ] Gamma [ ] Locked [ ] other: _______	[ ] CAN-cancellous [ ] CO - cortical	[ ] Yes [ ] No	[ ]AU – Autologous; Harvest Site: _______________ [ ]All – Allograft [ ] Commercial Filling Name___________	[ ] Yes [ ] No
#___ ___________	[ ] PS – plate & screws [ ] IN – Intramedullary nails [ ] KW - Kierschner-wires	[ ]Rush #_____ [ ]Ender #_____ [ ]Kuntscher [ ] Zickel [ ] Gamma [ ] Locked [ ] other: _______	[ ] CAN-cancellous [ ] CO - cortical	[ ] Yes [ ] No	[ ]AU – Autologous; Harvest Site: _______________ [ ]All – Allograft [ ] Commercial Filling Name___________	[ ] Yes [ ] No

If there are more, make a copy of this page and attach.

14. (Continued)

B) Osteotomy

Site # / Description	**Fixation**	**If Intramedullary nails specify which**	**Cancellous or Cortical Bone Graft**	**Bone Graft Material**	**Plaster Cast**
#___ __________	[ ] PS – plate & screws [ ] IN – Intramedullary nails [ ] KW - Kierschner-wires	[ ]Rush #_____ [ ]Ender #_____ [ ]Kuntscher [ ] Zickel [ ] Gamma [ ] Locked [ ] other: ________	[ ] CAN-cancellous [ ] CO - cortical	[ ]AU – Autologous; Harvest Site: __________________ [ ]All – Allograft [ ] Commercial Filling Name____________	[ ] Yes [ ] No
#___ __________	[ ] PS – plate & screws [ ] IN – Intramedullary nails [ ] KW - Kierschner-wires	[ ]Rush #_____ [ ]Ender #_____ [ ]Kuntscher [ ] Zickel [ ] Gamma [ ] Locked [ ] other: ________	[ ] CAN-cancellous [ ] CO - cortical	[ ]AU – Autologous; Harvest Site: __________________ [ ]All – Allograft [ ] Commercial Filling Name____________	[ ] Yes [ ] No
#___ __________	[ ] PS – plate & screws [ ] IN – Intramedullary nails [ ] KW - Kierschner-wires	[ ]Rush #_____ [ ]Ender #_____ [ ]Kuntscher [ ] Zickel [ ] Gamma [ ] Locked [ ] other: ________	[ ] CAN-cancellous [ ] CO - cortical	[ ]AU – Autologous; Harvest Site: __________________ [ ]All – Allograft [ ] Commercial Filling Name____________	[ ] Yes [ ] No
#___ __________	[ ] PS – plate & screws [ ] IN – Intramedullary nails [ ] KW - Kierschner-wires	[ ]Rush #_____ [ ]Ender #_____ [ ]Kuntscher [ ] Zickel [ ] Gamma [ ] Locked [ ] other: ________	[ ] CAN-cancellous [ ] CO - cortical	[ ]AU – Autologous; Harvest Site: __________________ [ ]All – Allograft [ ] Commercial Filling Name____________	[ ] Yes [ ] No
#___ __________	[ ] PS – plate & screws [ ] IN – Intramedullary nails [ ] KW - Kierschner-wires	[ ]Rush #_____ [ ]Ender #_____ [ ]Kuntscher [ ] Zickel [ ] Gamma [ ] Locked [ ] other: ________	[ ] CAN-cancellous [ ] CO - cortical	[ ]AU – Autologous; Harvest Site: __________________ [ ]All – Allograft [ ] Commercial Filling Name____________	[ ] Yes [ ] No
#___ __________	[ ] PS – plate & screws [ ] IN – Intramedullary nails [ ] KW - Kierschner-wires	[ ]Rush #_____ [ ]Ender #_____ [ ]Kuntscher [ ] Zickel [ ] Gamma [ ] Locked [ ] other: ________	[ ] CAN-cancellous [ ] CO - cortical	[ ]AU – Autologous; Harvest Site: __________________ [ ]All – Allograft [ ] Commercial Filling Name____________	[ ] Yes [ ] No

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14. (Continued)

C) Resection of the effected bone segment and replacement

Site # / Description	Fixation	If Intramedullary nails specify which	Cancellous or Cortical Bone Graft	Vascularized	Bone Graft Material	Plaster Cast
#___ ___________	[ ] PS – plate & screws [ ] IN – Intramedullary nails [ ] KW - Kierschner-wires	[ ]Rush #_____ [ ]Ender #_____ [ ]Kuntscher [ ] Zickel [ ] Gamma [ ] Locked [ ] other: _______	[ ] CAN-cancellous [ ] CO - cortical	[ ] Yes [ ] No	[ ]AU – Autologous; Harvest Site: _________________ [ ]All – Allograft [ ] Commercial Filling Name____________	[ ] Yes [ ] No
#___ ___________	[ ] PS – plate & screws [ ] IN – Intramedullary nails [ ] KW - Kierschner-wires	[ ]Rush #_____ [ ]Ender #_____ [ ]Kuntscher [ ] Zickel [ ] Gamma [ ] Locked [ ] other: _______	[ ] CAN-cancellous [ ] CO - cortical	[ ] Yes [ ] No	[ ]AU – Autologous; Harvest Site: _________________ [ ]All – Allograft [ ] Commercial Filling Name____________	[ ] Yes [ ] No
#___ ___________	[ ] PS – plate & screws [ ] IN – Intramedullary nails [ ] KW - Kierschner-wires	[ ]Rush #_____ [ ]Ender #_____ [ ]Kuntscher [ ] Zickel [ ] Gamma [ ] Locked [ ] other: _______	[ ] CAN-cancellous [ ] CO - cortical	[ ] Yes [ ] No	[ ]AU – Autologous; Harvest Site: _________________ [ ]All – Allograft [ ] Commercial Filling Name____________	[ ] Yes [ ] No
#___ ___________	[ ] PS – plate & screws [ ] IN – Intramedullary nails [ ] KW - Kierschner-wires	[ ]Rush #_____ [ ]Ender #_____ [ ]Kuntscher [ ] Zickel [ ] Gamma [ ] Locked [ ] other: _______	[ ] CAN-cancellous [ ] CO - cortical	[ ] Yes [ ] No	[ ]AU – Autologous; Harvest Site: _________________ [ ]All – Allograft [ ] Commercial Filling Name____________	[ ] Yes [ ] No
#___ ___________	[ ] PS – plate & screws [ ] IN – Intramedullary nails [ ] KW - Kierschner-wires	[ ]Rush #_____ [ ]Ender #_____ [ ]Kuntscher [ ] Zickel [ ] Gamma [ ] Locked [ ] other: _______	[ ] CAN-cancellous [ ] CO - cortical	[ ] Yes [ ] No	[ ]AU – Autologous; Harvest Site: _________________ [ ]All – Allograft [ ] Commercial Filling Name____________	[ ] Yes [ ] No
#___ ___________	[ ] PS – plate & screws [ ] IN – Intramedullary nails [ ] KW - Kierschner-wires	[ ]Rush #_____ [ ]Ender #_____ [ ]Kuntscher [ ] Zickel [ ] Gamma [ ] Locked [ ] other: _______	[ ] CAN-cancellous [ ] CO - cortical	[ ] Yes [ ] No	[ ]AU – Autologous; Harvest Site: _________________ [ ]All – Allograft [ ] Commercial Filling Name____________	[ ] Yes [ ] No

If there are more, make a copy of this page and attach.

14. (Continued)

D) Autogenous bone marrow graft into the dysplastic bone (Wientroub method).

Site # / Description	Fixation	If Intramedullary nails specify which	Cancellous or Cortical Bone Graft	Vascularized	Bone Graft Material	Plaster Cast
#___ ___________	[ ] PS – plate & screws [ ] IN – Intramedullary nails [ ] KW - Kierschner-wires	[ ]Rush #_____ [ ]Ender #_____ [ ]Kuntscher [ ] Zickel [ ] Gamma [ ] Locked [ ] other: _______	[ ] CAN-cancellous [ ] CO - cortical	[ ] Yes [ ] No	[ ]AU – Autologous; Harvest Site: ________________ [ ]All – Allograft [ ] Commercial Filling Name____________	[ ] Yes [ ] No
#___ ___________	[ ] PS – plate & screws [ ] IN – Intramedullary nails [ ] KW - Kierschner-wires	[ ]Rush #_____ [ ]Ender #_____ [ ]Kuntscher [ ] Zickel [ ] Gamma [ ] Locked [ ] other: _______	[ ] CAN-cancellous [ ] CO - cortical	[ ] Yes [ ] No	[ ]AU – Autologous; Harvest Site: ________________ [ ]All – Allograft [ ] Commercial Filling Name____________	[ ] Yes [ ] No
#___ ___________	[ ] PS – plate & screws [ ] IN – Intramedullary nails [ ] KW - Kierschner-wires	[ ]Rush #_____ [ ]Ender #_____ [ ]Kuntscher [ ] Zickel [ ] Gamma [ ] Locked [ ] other: _______	[ ] CAN-cancellous [ ] CO - cortical	[ ] Yes [ ] No	[ ]AU – Autologous; Harvest Site: ________________ [ ]All – Allograft [ ] Commercial Filling Name____________	[ ] Yes [ ] No
#___ ___________	[ ] PS – plate & screws [ ] IN – Intramedullary nails [ ] KW - Kierschner-wires	[ ]Rush #_____ [ ]Ender #_____ [ ]Kuntscher [ ] Zickel [ ] Gamma [ ] Locked [ ] other: _______	[ ] CAN-cancellous [ ] CO - cortical	[ ] Yes [ ] No	[ ]AU – Autologous; Harvest Site: ________________ [ ]All – Allograft [ ] Commercial Filling Name____________	[ ] Yes [ ] No
#___ ___________	[ ] PS – plate & screws [ ] IN – Intramedullary nails [ ] KW - Kierschner-wires	[ ]Rush #_____ [ ]Ender #_____ [ ]Kuntscher [ ] Zickel [ ] Gamma [ ] Locked [ ] other: _______	[ ] CAN-cancellous [ ] CO - cortical	[ ] Yes [ ] No	[ ]AU – Autologous; Harvest Site: ________________ [ ]All – Allograft [ ] Commercial Filling Name____________	[ ] Yes [ ] No
#___ ___________	[ ] PS – plate & screws [ ] IN – Intramedullary nails [ ] KW - Kierschner-wires	[ ]Rush #_____ [ ]Ender #_____ [ ]Kuntscher [ ] Zickel [ ] Gamma [ ] Locked [ ] other: _______	[ ] CAN-cancellous [ ] CO - cortical	[ ] Yes [ ] No	[ ]AU – Autologous; Harvest Site: ________________ [ ]All – Allograft [ ] Commercial Filling Name____________	[ ] Yes [ ] No

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Patient #: __ __ __

Optional Questions

The following questions are optional. Any information you provide can be very helpful in the study of this disease.

1. Has your patient had any other problems in your life, past or present, related to or as a result of his/her FD?

   [ ] inability to engage in athletics, since what age _____
   [ ] difficulty walking, since age _____
   [ ] walk with crutches/cane, since what age _____
   [ ] use ambulator, since what age _____
   [ ] use wheelchair, since what age _____
   [ ] wheelchair bound, since what age _____
   [ ] difficulty performing activities of daily living, since age _____
   activities of daily living = bathing, eating, combing hair, etc.

2. What was his/her age when he/she started puberty? _____

3. Was there any change (improvement or worsening) in your bone disease with around puberty status? From the list below please indicate wether the symptom got better, worse or had no change.

Symptom	Better	Worse	No change
Pain	[ ]	[ ]	[ ]
Limp	[ ]	[ ]	[ ]
Vision/hearing	[ ]	[ ]	[ ]
Fracture	[ ]	[ ]	[ ]
Swelling	[ ]	[ ]	[ ]
Headache	[ ]	[ ]	[ ]
Deformity	[ ]	[ ]	[ ]
Abnormal growth	[ ]	[ ]	[ ]

(if patient is male, go on to next page)

4. Has the patient entered menopause?

[ ] yes [ ] no
(if no, go on to next page)

What age did menopause begin? _____

What caused the menopause to begin

[ ] natural (spontaneous)
[ ] the result of surgery

[display only if above checked]
If surgical, were her ovaries removed?

[ ] yes [ ] no

[ ] the result of chemotherapy

[display only if above checked]
If chemotherapy, for what reason was it received?

_____

Was there any change (improvement or worsening) in her bone disease with menopause? From the list below please indicate whether the symptom got better, worse or had no change.

Symptom	Better	Worse	No change
Pain	[ ]	[ ]	[ ]
Limp	[ ]	[ ]	[ ]
Vision/hearing	[ ]	[ ]	[ ]
Fracture	[ ]	[ ]	[ ]
Swelling	[ ]	[ ]	[ ]
Headache	[ ]	[ ]	[ ]
Deformity	[ ]	[ ]	[ ]
Abnormal growth	[ ]	[ ]	[ ]

5. Has your patient been diagnosed with the McCune-Albright syndrome (MAS)?

   [ ] yes [ ] no

6. Does your patient have café-au-lait spots (or birthmarks) areas of darkened skin, the color of coffee with cream in it)?

   [ ] yes [ ] no
   (if no, go on to next page)

   Do the spots have smooth or irregular borders?

   [ ] irregular [ ] smooth

   How many spots did he/she have at birth _____?

   How many spots does he/she have now _____?

   Have the size of the spots
   [ ] increased [ ] decreased [ ] remained the same

   Which side of the body are the majority of the café-au-lait spots?

   [ ] right [ ] left [ ] fairly equal

   Is there any correlation between the side of the body on which most of the café-au-lait spots are and the FD? That is, is there a relationship between the side of the body which has the most café-au-lait spots and the side which has the most FD? Are they on the same or opposite sides?

   [ ] no relationship [ ] same side [ ] opposite sides

7. Does your patient or did your patient have precocious puberty? The signs of precocious puberty are:

   [ ] yes [ ] no
   (if no, go on to question 9)

   At what age did the precocious puberty start: _____

   Were any therapies (medicines and/or surgeries) used for the precocious puberty in the past?

   [ ] Medical [ ] Surgical [ ] None

8. Does he/she currently have precocious puberty?

   [ ] yes [ ] no
   (if no, go on to question 9

   Is he/she currently having any therapy for precocious puberty?

   [ ] Medical [ ] Surgical [ ] None
   (if none, go on to question 9)

   Is the therapy effective at controlling the symptoms of precocious puberty?
   [ ] yes [ ] no

9. Was there any change (improvement or worsening) in the bone disease with or around the start of puberty? From the list below please indicate wether the symptom got better, worse or had no change.

Symptom	Better	Worse	No change
Pain	[ ]	[ ]	[ ]
Limp	[ ]	[ ]	[ ]
Vision/hearing	[ ]	[ ]	[ ]
Fracture	[ ]	[ ]	[ ]
Swelling	[ ]	[ ]	[ ]
Headache	[ ]	[ ]	[ ]
Deformity	[ ]	[ ]	[ ]
Abnormal growth	[ ]	[ ]	[ ]

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10. Does your patient have thyroid disease?

[ ] yes [ ] no [ ] never tested
(if not yes, go on to next page)

At what age did it start? _____

What is the nature of your thyroid disease?

[ ] hyperthyroidism (elevated thyroid function)
[ ] hypothyroidism (low thyroid function)
[ ] benign thyroid nodule(s)
[ ] thyroid cancer

Has there been any treatment for thyroid disease?

[ ] Medical [ ] Surgical [ ] None

Was there any change (improvement or worsening) in the bone disease with the onset of thyroid disease? From the list below please indicate whether the symptom got better, worse or had no change.

Symptom	Better	Worse	No change
Pain	[ ]	[ ]	[ ]
Limp	[ ]	[ ]	[ ]
Vision/hearing	[ ]	[ ]	[ ]
Fracture	[ ]	[ ]	[ ]
Swelling	[ ]	[ ]	[ ]
Headache	[ ]	[ ]	[ ]
Deformity	[ ]	[ ]	[ ]
Abnormal growth	[ ]	[ ]	[ ]

Was there any change (improvement or worsening) in the bone disease during the treatment of the thyroid disease?.

Symptom	Better	Worse	No change
Pain	[ ]	[ ]	[ ]
Limp	[ ]	[ ]	[ ]
Vision/hearing	[ ]	[ ]	[ ]
Fracture	[ ]	[ ]	[ ]
Swelling	[ ]	[ ]	[ ]
Headache	[ ]	[ ]	[ ]
Deformity	[ ]	[ ]	[ ]
Abnormal growth	[ ]	[ ]	[ ]

11. Has your patient been diagnosed with hypersecretion of any pituitary hormones? That is high growth hormone (causing acromegaly), high prolactin, high ACTH (causing Cushing's disease), high thyroid stimulating hormone (causing hyperthyroidism)?

    [ ] yes [ ] no [ ] Don't Know
    (if not yes, go on to next page)

    Which hormone(s)?

Hormone	Age started	Treatment
[ ] growth hormone	_____	_____
[ ] prolactin	_____	_____
[ ] ACTH	_____	_____
[ ] TSH	_____	_____

    What did the elevation of the hormone do to the bone disease symptoms? From the list below please indicate whether the symptom got better, worse or had no change.

Symptom	Better	Worse	No change
Pain	[ ]	[ ]	[ ]
Limp	[ ]	[ ]	[ ]
Vision/hearing	[ ]	[ ]	[ ]
Fracture	[ ]	[ ]	[ ]
Swelling	[ ]	[ ]	[ ]
Headache	[ ]	[ ]	[ ]
Deformity	[ ]	[ ]	[ ]
Abnormal growth	[ ]	[ ]	[ ]

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12. Has your patient been diagnosed as having elevated secretion of hormone(s) from the adrenal gland (cortisol, aldosterone)?

Hormone	Age diagnosed	Treatment
[ ] cortisol	_____	_____
[ ] aldosterone	_____	_____

[ ] None
(if none, go on to next page)

What effect did the elevation of the hormone have on the bone disease symptoms?

Symptom	Better	Worse	No change
Pain	[ ]	[ ]	[ ]
Limp	[ ]	[ ]	[ ]
Vision/hearing	[ ]	[ ]	[ ]
Fracture	[ ]	[ ]	[ ]
Swelling	[ ]	[ ]	[ ]
Headache	[ ]	[ ]	[ ]
Deformity	[ ]	[ ]	[ ]
Abnormal growth	[ ]	[ ]	[ ]

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13. Has your patient been diagnosed as having an elevation of parathyroid hormone?

[ ] yes [ ] no
(if no, go on to next page)

At what age was it diagnosed: _____.

Describe any treatment provided for this condition:
_____

What effect did it have on the bone disease symptoms?

Symptom	Better	Worse	No change
Pain	[ ]	[ ]	[ ]
Limp	[ ]	[ ]	[ ]
Vision/hearing	[ ]	[ ]	[ ]
Fracture	[ ]	[ ]	[ ]
Swelling	[ ]	[ ]	[ ]
Headache	[ ]	[ ]	[ ]
Deformity	[ ]	[ ]	[ ]
Abnormal growth	[ ]	[ ]	[ ]

14. Has your patient been diagnosed as having hypophosphatemia?

[ ] yes [ ] no [ ] never tested/don't know
(if no, go on to question 15)

At what age was it diagnosed: _____.

Describe any treatment provided for this condition:
_____

What effect did it have on his/her bone disease symptoms?

Symptom	Better	Worse	No change
Pain	[ ]	[ ]	[ ]
Limp	[ ]	[ ]	[ ]
Vision/hearing	[ ]	[ ]	[ ]
Fracture	[ ]	[ ]	[ ]
Swelling	[ ]	[ ]	[ ]
Headache	[ ]	[ ]	[ ]
Deformity	[ ]	[ ]	[ ]
Abnormal growth	[ ]	[ ]	[ ]

15. Has your patient been diagnosed as having rickets or osteomalacia?

[ ] yes [ ] no [ ] never tested/don't know

16. Does you patient have any bleeding dyscrasias?

[ ] tendency to bleed [ ] tendency to thrombose [ ] No dyscrasias

17. Has your patient required any transfusions? [ ] yes [ ] no [ ] don't know

18. Does you patient have or ever had low vitamin D?

[ ] yes [ ] no [ ] don't know

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19. Does your patient have any renal problems?

[ ] nephrolithiasis
[ ] proteinuria
[ ] aminoaciduria
[ ] calciuria
[ ] phosphaturia
[ ] insufficiency
[ ] hyperfiltration
[ ] none

20. Does your patient have any unrelated (unrelated to FD or MAS as far as you know) medical problems?

[ ] yes [ ] no

21. If yes, please list them:

1. _____
2. _____
3. _____
4. _____
5. _____

22. List any other medications your patient takes which have not already been mentioned:

1. _____
2. _____
3. _____
4. _____
5. _____